DOCUMENT RESUME

ED 473 270 RC 023 924

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TITLE	A Brief History of and Future Considerations for Research in American Indian and Alaska Native Communities.
PUB DATE	2002-04-00
NOTE	11p.; In: Work Group on American Indian Research and Program Evaluation Methodology (AIRPEM), Symposium on Research and Evaluation Methodology: Lifespan Issues Related American Indians/Alaska Natives with Disabilities; see RC 023 923.
AVAILABLE FROM	For full text of entire monograph: http://www4.nau.edu/ihd/airrtc/pdfs/monograph.pdf.
PUB TYPE	Information Analyses (070) -- Speeches/Meeting Papers (150)
EDRS PRICE	EDRS Price MF01/PC01 Plus Postage.
DESCRIPTORS	Action Research; American Indian History; *American Indians; Codes of Ethics; *Community Involvement; Cultural Relevance; *Ethnic Bias; *Participatory Research; *Research Methodology; *Research Problems; Tribes
IDENTIFIERS	*Research Ethics; Researcher Subject Relationship

ABSTRACT

Historical views about individuals and communities shape the ways that researchers interact with people and their communities. The European settlers thought of Native Americans as savages in need of socialization. Accordingly, the first researchers had little concern for the needs of Native people and their communities and sought to impose Western scientific values to solve Native communities' problems. From the communities' perspective, forced acculturation, exploitation, and other injustices contributed to feelings of inferiority and mistrust of investigators and the research process. More recently, significant strides have been made in involving American Indians and Alaska Natives as partners in research. Participatory research methods and tribal research codes of ethics have helped transform the research process into one that is beneficial to both the communities and the researchers. This paper provides an historical overview of research practices on Native communities (paternalism) with Native Americans, in true collaboration with Native communities, and describes best practices in participatory action research. Three formal and one informal tribal codes of research ethics are briefly described, and principles of "cultural case formulation" from the Diagnostic and Statistical Manual of Mental Disorders (DSM) are presented. (Contains 31 references.) (Author/SV)

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A Brief History of and Future Considerations for Research in American Indian and Alaska Native Communities

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Abstract

The authors explore the relationship between the historical treatment of American Indian and Alaska Native people and research practices in these communities. Forced acculturation, exploitation, and other injustices contributed to feelings of inferiority and mistrust of investigators as well as of the research process. Participatory research methods and tribal research codes of ethics have helped transform the research process for American Indian and Alaska Native communities to one that is beneficial for Native people as well as for researchers. Future research needs in American Indian and Alaska Native communities are discussed.

Historical views about individuals and communities shape the ways that researchers interact with people and their communities. The European settlers thought of Native Americans as savages in need of socialization. Accordingly, as scientists began investigating American Indians, there was little concern for the needs of these people and their communities. "Civilization" brought new diseases and social problems to these communities and, with them, an opportunity for researchers to impose Western scientific values to solve these problems for Native communities. More recently, significant strides have been made in involving American Indians and Alaska Natives as partners in the study of physical, emotional, social, and environmental problems. Such partnerships are beneficial for researchers as well as for American Indian and Alaska Native people and their communities.

Although the focus of this paper is the indigenous peoples of what is now the United States and Canada, the need to develop true collaborations with indigenous people has no boundaries. It is in this spirit that we write this paper—with the hope that it will, in some small way, contribute positively to the health status of indigenous peoples and close the gap of health care disparities in these communities.

Historical Perspectives on Research in American Indian and Alaska Native Communities—Lessons Learned

Paternalism—Conducting Research on Native Americans

The mistreatment experienced by American Indians for centuries has resulted in little tolerance for non-Natives who wish to conduct research in Native communities. American Indians and Alaska Natives have come to believe that researchers often do not recognize the rich diversity of each Nation and, instead, may catalog the more than 500 federally recognized tribes as equivocally *Indian*. Acknowledging the diversity of Indian peoples and thus the uniqueness of each tribe is fundamental to gaining the trust and respect of the community. Few researchers understand the influence traditional values and beliefs have on the lifestyles of American Indian and Alaska Natives; for the scientist, such values rarely have significance for research (Davis & Reid, 1999). For American Indian and Alaska Native people, cultural values represent a way of life.

A relationship exists between the historical treatment of American Indian and Alaska Native people and the research methods used

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to study these individuals. A search of the Native Health History Database (http://hscapp.unm.edu/nhhd) by the authors of this paper revealed that published research has been conducted on American Indians since the early 19th century. Written accounts of American Indians certainly existed well before this time but were primarily observations made by missionaries and military personnel (e.g., see Oliver, 1764).

At best forced acculturation and at worst annihilation were imposed on the indigenous peoples of North America. The first reservation was established in Connecticut in 1638, officially signaling the beginning of relocation efforts—efforts that would later tear at the very fabric of the collective nature of all American Indian communities (Equity Center Infoline, 1999). Native communities, entire tribes in many instances, were destroyed. Following this period of destruction and initial relocation came the second phase of extensive relocation and forced removal of the early- to mid-1800s. Research written during this historical era reflects the Eurocentric beliefs about American Indians. One such example is the 1857 article authored by Dowler titled *Researches into the Sanitary Condition and Vital Statistics of Barbarians*. American Indians were considered savages incapable of caring for themselves, much less of engaging in scholarly activities such as conducting research. Although the many efforts of the U.S. Government (e.g., forced removal and distribution of disease-infected blankets) were unsuccessful at destroying the Native Americans, new strategies were employed.

In 1879, the Carlisle Indian School was established in Pennsylvania. The motto of Carlisle was "Kill the Indian, save the Man" (Styron, 1997). This *new* method, assimilation, although different from forced removal and genocide, was no less destructive to the individuals and communities exposed to boarding school policy. An 1872 statement by George Grant, a Presbyterian minister who traveled across North America documenting his observations, was prophetic:

> As the Indian has no chance of existence except by conforming to civilized ways, the sooner that the Government or the Christian people awake to the necessity of establishing schools among every tribe the better. Little can be done with the old, and it may be two, three or more generations before the old habits of a people are changed; but, by always taking hold of the young, the work can be done (Styron, 1997).

Research of this era supported this notion that western education was the only hope to reform the *amoral* practices of Native Americans. Elliott authored one such article, "Wild Babies," in 1878.

Federal legislation mandated compulsory schooling for Natives. By 1887 there were 167 schools both on and off the reservations with an enrollment of nearly 15,000. In 1902, of the nearly 200 Indian schools, 25 were federally sponsored off-reservation. The number of boarding schools continued to increase throughout the early 1900s; such schools were located in over 15 states and territories (The Brown Quarterly, 2001; Equity Center Infoline, 1999).

Although sympathizers with the "Indian condition" were increasing in numbers, research practices were paternalistic. Even though many American Indians experienced considerable injustices at the hands of educators and missionaries, the education these individuals received undoubtedly contributed to the eventual evolution of research practices in American Indian and Alaska Native communities.

Interestingly, it was not until 1924 that all American Indians were granted U.S. citizenship (American Indian Lawyer Training Program, Inc., 1988). The paternalistic approach to interactions with and research on Native peoples continued into the 20th century. Research conducted in the 1920s through the 1940s included *Mental Disease Situations in Certain Cultures—A New Field for*

Research (Cooper, 1934), *Medical Observations Made on Zuni Indians* (Flemming, 1923), and *Studies in the Dietaries of Contemporary Primitive Peoples* (Klatsky, 1948).

During the 1950s the U.S. Government again decided it knew what was best for American Indian people. The years between 1953 and 1962 are known as the "termination experiment" (American Indian Lawyer Training Program, Inc., 1988, p. 13). These are the years of the Termination Acts. The federal government believed that over 100 American Indian tribes should be able to assimilate into the larger society without the benefits and services afforded through trust responsibilities (American Indian Lawyer Training Program, Inc., 1988).

During this period it was not uncommon for researchers to collect data without the full knowledge and consent of participants and without respect for local culture and tradition (Hodge, Weinmann, & Roubideaux, 2000; Macaulay, 1994). At one time (and even in contemporary times), it was not uncommon for *helicopter research* (Hodge et al., 2000) to take place in Native communities. The term helicopter research describes the way in which investigators *fly in* to collect the data and *fly out*, having little or no interaction with the community. These researchers leave without obtaining community endorsement or considering the needs of the community, to publish findings that tell only of the health and health care disparities and problems found in the American Indian and Alaska Native communities studied. Often community members are unaware of the purpose of the study; benefits to the community are unknown. Such research practices have led to feelings of exploitation and inferiority when researchers try to gain entry into a Native community. This can result in an unsuccessful research project (Davis & Reid, 1999). Many tribal communities have become protective and, at times, prohibit researchers from their communities.

Joining—Conducting Research with *Native Americans*

Although research practices continued to neglect the needs of American Indian and Alaska Native communities, the evolution of anthropology and social science research, coupled with the changing political climate in the U.S., led to some changes in the way research was conducted in these communities. The Nixon administration passed the Indian Self-Determination and Education Assistance Act (Pub. L. 93-638) in 1975, supporting the autonomy of American Indian and Alaska Native communities (Kunitz, 1996). Although first developed in the early 1960s, the Indian Health Service (IHS) policies, procedures, and responsibilities for research activities were significantly updated in 1977, 1982, and 1987. These new policy documents set forth the guidelines and oversight for research activities, including the Protection of Human Subjects, the IHS Institutional Review Board (IRB), Area Research Committees, and the Director of Research (Indian Health Manual, 2001). In addition, a latent benefit of assimilation and forced education was emerging; American Indians and Alaska Natives were obtaining advanced degrees and beginning to influence the research process. Carolyn Attneave, a Delaware and Cherokee psychologist, is one such example. Her work on the importance of culture for families and communities helped change the way researchers thought about and conducted research (see, e.g., Attneave, 1982).

During the 1970s, researchers began working *with* Native communities—that is, they began to involve Native communities in the research process, but still without true collaboration. Consideration for American Indian and Alaska Native community needs is evident in the research of this era. Several examples of research during this period are representative of this paradigm shift. Patrick and Tyroler's (1972) research, reported in *Papago Indian Modernization: A Community Scale for Health Research,* focused on community needs; Taylor (1975) consulted with tribal members in

developing his *Cherokee Tribal Health Evaluation Report*, and Brelsford (1977) authored *Cgwangkumtenek Sungcarluta*, consulted with Alaska Natives, and incorporated Alaska Native language into his paper.

Consultation is not collaboration. Foulks (1989) candidly discussed the mistakes made and the resulting misalliances in a study of alcohol use among the Inupiat. Although the investigators established a Steering Committee that consisted of local Inupiat leaders and a Technical Advisory Group (mostly made up of non-Native professionals), the investigators were unable to reach consensus about the content of the report in conjunction with the Steering Committee and the Technical Advisory Group. When a press statement was released about the results of the study the headlines read, "Sudden Wealth Sparks Epidemic of Alcoholism: What We Have Here is a Society of Alcoholics" (Foulks, 1989, p. 13). The community was outraged. A non-Native faculty member of the Inupiat University of the Arctic summed up this outrage:

> [T]he North Slope Borough Assembly has been the victim of a sophisticated hoax aimed at destroying the credibility and integrity of the Inupiat people. The research on alcohol abuse and the news coverage was the most demeaning and reprehensible sham. Instead of using Winchester and Remington rifles to destroy a people and a culture, as with the Indians in the 1880s, they bent words, numbers, and statistics to accomplish what was in effect a social and cultural genocide. These con artists hiding behind the guise of professionalism and religiosity, and acting as consultants to the North Slope Borough have dealt a devastating blow to the Inupiat people and their cultural heritage (Foulks, 1989, pp. 14-15).

Such violations of trust by researchers in American Indian and Alaska Native communities negatively affected the willingness of these communities to participate in the research process (Norton & Manson, 1996).

Even the most recent research sometimes overlooks the nuances important for conducting research in American Indian and Alaska Native communities. In an important and generally well developed study of recruiting American Indians and Alaska Natives into clinical trials (Hodge et al., 2000), the term *subjects* is still used to describe research participants. Such language minimizes the value of the individuals who partner with researchers.

Collaborating—Conducting Research in a Participatory *Fashion*

Participatory Research

Research has quantified and described some of the realities of American Indian and Alaska Native people but has contributed little to improve this reality (Dickson & Green, 2001). Despite the problems of the past, American Indians and Alaska Natives realize the need for research and health promotion projects in their communities. *Participatory research* (PR) represents an active step in improving research so that the research benefits the communities studied. Simply stated, PR empowers people to become responsible for addressing the issues that affect their lives.

Participatory research begins with the idea that people can and must benefit from the research conducted in their communities. It is important that both scientists and community members share equally in the research planning, implementation, evaluation, and results dissemination phases as well as in any resulting benefits (Davis & Reid, 1999). The principles of PR clearly define the roles of the partners who are collaborating for the benefit of the community. The ultimate goal of participatory research is to empower communities to assume ownership of the research process and to utilize the results to improve their quality of life (Macaulay et al., 1998). Only research that primarily considers the interest(s) of the community, not just the interest(s) of the larger

society, can bring significant benefits to the community served.

Researchers must approach the community in a respectful manner. A community meeting that explains, in layman's terms, the goals of the project to all interested community members will allow for questions to be answered and misunderstandings to be addressed. "In recent years, many tribes have formed their own Institutional Review Boards (IRB) to obtain some degree of control in the research process and to halt the perceived misuse and misinterpretation of data" (Hodge et al., 2000, p. 43). Tribes evaluate research projects to determine whether hypotheses are of interest or results will provide benefits to the tribe; researchers must gain the approval of the tribal IRB. "Obtaining consent from tribal governments may involve significant time, preparation, and expense, which must be considered in planning grant applications and project deadlines" (Norton & Manson, 1996, p. 858). If research is to be conducted at an IHS facility, approval from the IHS IRB must be obtained.

"It is not necessary for the researcher to know all the cultural distinctions. Rather, it is important that the researcher be aware of cultural differences" (Hodge et al., 2000, p. 43). Researchers are not expected to be experts on the more than 500 American Indian tribes and Alaska Native villages, but should learn as much as possible about the local community and tribe they plan to study. Investigators may become involved in the community through attending tribal meetings and social gatherings. Learning more about the history and culture of the tribe as well as local customs and beliefs about illness will allow the researchers to conduct a more efficient study that will prove successful to both parties involved. Showing genuine concern as well as a willingness to learn and be a part of the community can foster trust.

Once the tribe or community has consented to or approved a research project, guidelines should be established collaboratively between the community and researchers. A Code of Research Ethics was developed in partnership with the Native Mohawk community of Kahnawake in Canada (Macaulay et al., 1998). The document demonstrates new concepts in the sharing of power and decision making for both the researchers and the community. Guidelines for conducting PR entail developing a policy statement, discussing the obligations of all parties involved, developing a data control plan, and developing a plan for disseminating results.

The Kahnawake policy statement ensures that the cultural values, perspectives, and wishes of the community are firmly incorporated into the research plan; they emphasize the need for community empowerment (Macaulay et al, 1998). The following is an excellent example of a policy statement:

> The sovereignty of the Kanien'keha:ka (the people) of Kahnawake to make decisions about research in Kahnawake is recognized and respected. The benefits to the community as a whole and to individual community volunteers should be maximized by the researchers. Researchers should empower the community to support community goals of health and wellness, to promote healthy lifestyles, improve self-esteem and to fulfill its traditional responsibility of caring for the Seventh Generation. (In Mohawk tradition, the Seventh Generation represents those as yet unborn) (p. 107).

The obligations of the researchers include maintaining continuous consultation and collaboration on all aspects of the research, involving the community through active participation rather than passive acceptance, transferring new skills to the community during the research process, and helping to address any health or social issues raised as a result of the research.

The obligation of community-based researchers is to maintain a long-term relationship of trust in their dual role as

caregivers-educators and researchers. The needs of the community should retain priority in any decision. The obligations of the community include meeting regularly with the researchers, promoting the objectives of the project, offering advice for the development and interpretation of the study, controlling the data after the project ends, and providing dissenting opinions, if needed, at the time of publication.

Community control of the data throughout the research process can help ensure appropriate use of the data (Macaulay et al., 1998). The community maintains control over the dissemination of the results in the PR model. The ultimate decision on how the results are to be used, including whether to publish in scientific journals, resides with the community. Results should be presented to the tribal council and community members in a form that is interpretable and meaningful as well as in a manner that may be used by service providers and administrators (Macaulay et al., 1998, Norton & Manson, 1996).

The study of diabetes mellitus and atherosclerosis in a Mohawk community (Montour & Macaulay, 1988) provides insight about successful dissemination of results. The findings of this study pointed to the serious negative consequences of diabetes for the community. The results were presented to various community groups over several sessions as well as broadcast on the local community radio station. Immediately after the results had been distributed, the Health Department began to note an increase in the number of people being screened for diabetes and seeking counseling for dietary changes, weight loss, and exercise. The schools banned junk food and initiated a daily exercise period for all faculty and students. This study, and the way the results were presented, led to a positive change within the Mohawk community.

Participatory Action Research[1]*: Lessons Learned with Aboriginal Grandmothers*

A two-and-a-half year program was designed to examine the unmet health needs of older urban aboriginal women and to study *participatory action research* (PAR) as a research method and intervention for health promotion (Dickson & Green, 2001). The primary goal of the assessment was to strengthen the Grandmothers' sense of self-worth. The Grandmothers' initial response was that research was *something done to them* for the benefit of the outsiders. The project was a success because the researchers partnered with the Grandmothers. A sense of community was fostered between the Grandmothers and researchers. The Grandmothers' roles in the research process were highly valued; they designed interview guides, consent forms, work plans and contracts, and provided secondary analysis and verification for interpretation of the data. The final report consisted largely of the Grandmothers' words and was approved and released only after extensive review. "Faith in the long-term process is essential for all participants of PAR because social and political change does not occur readily" (Dickson & Green, 2001, p. 481). The project concluded that, given the opportunity, support, and tools, Native people have the capacity to conduct research that is meaningful to them and contributes to their personal and social change.

Participatory research balances the needs and wants of the community with those of the researchers; without this balance trust may be broken and significant problems may arise. The *give and take* approach is one that allows community members and researchers to

[1]PAR goes beyond PR by insisting that researchers offer tribes the support and tools to implement (i.e., take action) the research findings that will enable tribes to develop effective and culturally appropriate intervention and prevention programs. A body of literature discussing the differences of PAR and PR exists and a review is beyond the scope of this paper (see Marshall et al., this monograph).

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remain equal partners; if researchers make use of participants' ideas, time, and/or bodily fluids, they must give back skills, employment, and/or training (Davis & Reid, 1999). Communities will benefit from research by simply addressing relevant concerns of the tribes and other Native communities. "Researchers who demonstrate a long-term commitment to the communities that they propose to study, and who are willing to enter into the partnerships implied by such commitments, will receive greater cooperation and support of their work" (Norton & Manson, 1996, p. 859).

Best Practices

A number of research codes of ethics exist, specifically developed by American Indian and Alaska Native communities. Here we present, in chronological order, a brief description of three formalized and one informal ethics codes. Also included in this section is a brief presentation of "cultural case formulation" and its relevance for research.

Macaulay et al. (1996) developed a formalized code of research ethics to guide researchers as well as community members throughout the entire research process. The development of this ethics code involved academic researchers, community-based researchers, and the community in defining the various roles, from the initial research question and design of the project to the dissemination of research results. Specifically,

> The three partners will work cooperatively and collaboratively in the design, implementation, analysis, interpretation, conclusion, reporting, and publication of the experiences of the project. Each partner provides ideas and resources that come from the experience, knowledge, and capability of its members. Together, through respect for each other, consultation, and collaboration, they significantly strengthen the project and its outcomes. All three partners of the project share an understanding that community-based research is a powerful tool for learning about health and wellness, while contributing to the health of the community in which it is being conducted (p. 39).

The Model Tribal Research Code was developed by the American Indian Law Center, Inc. (1999). This 28-page document represents an extensive evaluation of the need for such a code for American Indian tribes and Alaska Native villages and presents information about the appropriate as well as the inappropriate uses of such a code. Specific aspects of developing a research code of ethics, including a discussion of policy statements, scope, process, and enforcement, are presented and discussed thoroughly. In addition, a Model Tribal Research Code template is included in the document as is a checklist to aid tribal health boards and others to evaluate effectively the appropriateness and usefulness of a research proposal.

Though not a formal ethics code, the Strong Heart Study (Stoddart, Jarvis, Blake, Fabsitz, Howard, Lee, & Welty, 2000), a large-scale multisite study of cardiovascular health, represents an excellent example of appropriate recruitment of American Indians into medical research. Collaboration with the IHS began early in the pre-award stage of the project and participating communities were involved in the proposal evaluation process and the methodology development process. Participating tribal members developed posters and logos used to inform and recruit community members. Brochures were developed to explain the purpose and rationale of the study, the procedures that would be utilized, and a community-identified point-of-contact who could answer questions and schedule appointments for participation in the study. Community-based recruiters contacted potential participants. Mass mailings and local radio broadcasts were used to promote participation in the study. Recruitment strategies included benefit powwows and health fair participation. The success of this study is attributed to the

multimethod recruitment strategy employed (i.e., meeting the various needs of potential participants) as well as to the respect for community needs, cultural differences, and the flexibility used to meet the needs of the researchers and the research participants.

The National Science Foundation Arctic Program developed Principles for the Conduct of Research in the Arctic (http://www.nsf.gov/od/opp/arctic/conduct.htm). These guidelines were developed to "promote mutual respect and communication between scientists and northern residents" (p. 1). The 13 principles emphasize the need to assess scientific investigations in terms of the potential impact on and interests of Native people and their communities. The recommendations outline the need to obtain full and informed consent explained in terms understandable to the community; to consult with the communities throughout the research process; to communicate results in a manner responsive to community needs; to provide appropriate credit for community contributions; and to respect anonymity, local cultural traditions, cultural property, and sacred sites.

Historically, the Diagnostic and Statistical Manual of Mental Disorders (DSM) has paid little attention to the role of culture for psychiatric diagnosis. The Fourth Edition of the DSM (American Psychiatric Association, 1994) breaks from this tradition and acknowledges the importance of culture for "the expression, course, treatment, and existence of psychiatric disorders" (Christensen, 2001, p. 53). Christensen discusses the relationship between cultural competence and psychiatric diagnosis and presents an example of cultural case formulation for an American Indian client. Cultural identity; cultural explanations of illness; the relationship among the psychosocial environment, culture, and levels of functioning; and cultural and social status differences between the individual and the clinician are components necessary to understanding the role of culture for the individual. Although not specifically designed for research purposes, these principles are relevant for researchers studying psychiatric disorders as well as researchers conducting nonclinical investigations.

The Future of Research in American Indian and Alaska Native Communities

Research practices have changed dramatically over the past 150 years. American Indian and Alaska Native communities demand that research benefit their people *and* that the research be conducted in a collaborative and participatory manner. Continuing to develop research that addresses the health needs of American Indian and Alaska Native people is of vital importance. The goal of this section is to foster thoughts about the future direction of research in these communities and for these people.

Research that addresses the use of direct service referrals by providers, employers, schools, union, family members, and self-referrals is needed. Such research will help communities understand how to make better use of available resources. Augmenting knowledge about service utilization rates can increase awareness about who is not being reached and how better to include these individuals. This type of research has particular relevance for elders and individuals with disabilities. Stigma also influences utilization rates. Understanding what contributes to stigma in a particular community, and what can done to minimize the effects of stigma, can help the community develop more effective outreach programs.

Encouraging employment of tribal members in tribal programs is necessary; however, important issues can occur when family members, friends, or neighbors provide services or work in these programs. Individuals may be reluctant to disclose information openly to community members if there are concerns about indiscreet use of personal information. For example, concerns about confidentiality may develop when

family members work for health programs. Research may be able to help us gain a better understanding about such issues.

Research often focuses on the *problems* or concerns faced by a community or group of individuals. Additional research focused on strengths is needed to help clinicians better utilize the inherent strengths of individuals and promote wellness.

Considering the history of problems relative to conducting research in American Indian and Alaska Native communities, considerable disparities exist in what we know about these communities as compared with what we know from research about the general population. Children, women, aftercare, violence, health care, traditional medicine—nearly every facet of life for Native people is fertile ground for investigation to benefit the people and the Nations.

Conclusion

Research is essential for understanding the health and well being of American Indian people. The usefulness of research is diminished when the community's vitality is overlooked. Communities are made up of people—individuals who live, breathe, and love, individuals who feel pain as well as joy. Several tribal research codes of ethics are available to aid investigators in designing appropriate research (e.g., American Indian Law Center, Inc., 1999; Macaulay et al., 1998). Existing models, such as the participatory action research method (Dickson & Green, 2001), provide practical examples of effective research practices in American Indian and Alaska Native communities. Both researchers and community members can benefit by establishing effective research partnerships.

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